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IN THE

Supreme Court of the United States

OCTOBER TERM, 1980

PENNHURST STATE SCHOOL AND HOSPITAL, et al.,
Petitioners,

v.

TERRI LEE HALDERMAN, et al.,
Respondents.

On Writ of Certiorari to the United States
Court of Appeals for the Third Circuit

AMICI CURIAE BRIEF OF THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS AND FORTY FIVE INDIVIDUAL STATE DEVELOPMENTAL DISABILITIES PROTECTION AND ADVOCACY SYSTEMS UNDER 42 U.S.C. §6012 FROM THE STATES OF ALABAMA, ALASKA, ARIZONA, ARKANSAS, CALIFORNIA, COLORADO, CONNECTICUT, DELAWARE, DISTRICT OF COLUMBIA, FLORIDA, GEORGIA, HAWAII, IDAHO, ILLINOIS, IOWA, KANSAS, KENTUCKY, LOUISIANA, MAINE, MARYLAND, MICHIGAN, MINNESOTA, MISSISSIPPI, MISSOURI, MONTANA, NEBRASKA, NEVADA, NEW HAMPSHIRE, NEW JERSEY, NEW MEXICO, NEW YORK, NORTH CAROLINA, NORTH DAKOTA, OREGON, PENNSYLVANIA, PUERTO RICO, RHODE ISLAND, TENNESSEE, TEXAS, UTAH, VERMONT VIRGIN ISLANDS, WEST VIRGINIA, WISCONSIN, AND WYOMING

ROBERT L. BURGDORF, JR.
Developmental Disabilities Law Project
500 West Baltimore Street
Baltimore, Maryland 21201
(301) 528-6307

Counsel for Amici Curiae

THE PAUL M. HARROD COMPANY, BALTIMORE, MARYLAND 21234

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Advocacy Services, Inc. (Arkansas)
Protection and Advocacy, Inc. (California)
Legal Center for Handicapped Citizens, Inc. (Colorado)
Office of Legal Protection and Advocacy for Handicapped and Developmentally Disabled Persons (Connecticut)
Community Legal Aid Society, Inc. (Delaware)
Information Center for Handicapped Individuals (District of Columbia)
Governor's Commission on Advocacy for Persons with Developmental Disabilities (Florida)
Georgia Advocacy Office, Inc.
Protection and Advocacy of Hawaii
Idaho's Coalition of Advocates for the Disabled
Illinois Developmentally Disabled Advocacy Authority
Protection and Advocacy Division of Iowa Civil Rights Commission
Kansas Advocacy and Protective Services for the Developmentally Disabled, Inc.
Office of Public Advocacy (Kentucky)
Advocates for the Developmentally Disabled (Louisiana)
The Advocates for the Developmentally Disabled (Maine)
Maryland Advocacy Unit for the Developmentally Disabled
Michigan Protection and Advocacy Service for Developmentally Disabled Citizens
Developmentally Disabled Advocacy Project (Minnesota)
Mississippi System of Protection and Advocacy for Developmentally Disabled Individuals, Inc.

Missouri Developmental Disabilities Protection and Advocacy Services,Inc.
Developmental Disabilities Montana Advocacy Program, Inc.
Nebraska Advocacy Services for Developmentally Disabled Citizens, Inc.
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Department of Public Advocate (New Jersey)
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Protection and Advocacy Project for the Developmentally Disabled (North Dakota)
Oregon Developmental Disabilities Advocacy Center
Developmental Disabilities Advocacy Network, Inc. (Pennsylvania)
Protection and Advocacy (Puerto Rico)
Rhode Island Protection and Advocacy System, Inc.
Tennessee State Planning Office
Advocacy, Inc. (Texas)
Legal Center for the Handicapped (Utah)
Vermont Developmental Disabilities Law Project
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INTEREST OF AMICI

This brief amicus curiae is filed, pursuant to consents filed with the Clerk, on behalf of the National Association of Protection and Advocacy Systems and forty-five individual state developmental disabilities protection and advocacy systems.

The National Association of Protection and Advocacy Systems is an organization consisting of the executive directors of the state protection and advocacy systems whose purpose is to further the human and legal rights of disabled persons, advance the interests of protection and advocacy systems, and facilitate coordination and provide mutual support among protection and advocacy systems.

Under Section 113 of the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. § 6012, each state is required to have in effect a system to protect and advocate the rights of developmentally disabled individuals. That system must have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons. The individual state protection and advocacy systems are organizations designated by their respective States to serve as the State's protection and advocacy agency.

As the present case concerns the enforceability of the very legislation which authorized the protection and advocacy systems and of the Bill of Rights provisions which they are charged with implementing, the *amici* have a very direct interest in the outcome of this case and significant expertise regarding the legislative history, interpretation, and impact of the legislation at issue. Failure of this Court to recognize the enforceability of the rights at stake in this case would seriously undercut the day-to-day efforts of the *amici* agencies to secure the rights of their clients and leave the protection and advocacy agencies with a mandate but no legal tools for achieving their statutory and state designated purposes.

SUMMARY OF ARGUMENT

Contrary to Petitioners' argument that the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 6000

et seq., is solely a funding statute, the legislative scheme of the Act is two-fold—it both continues federal financial support of comprehensive planning and service programs begun under prior legislation and establishes a set of legally enforceable rights of developmentally disabled persons. That Congress fully intended to depart from strictly a funding approach is made clear from three sources: the plain language of the statute, the report of the Joint Conference Committee accompanying the legislation, and the statements of various members of Congress during the floor debates on the legislation.

Throughout its history, developmental disabilities legislation has been characterized by a sensitivity to the strengths and differences of the individual states. The mechanisms created for the enforcement of the rights in the Bill of Rights Section of the 1975 Act, 42 U.S.C. § 6010, underscore the Congressional awareness of the unique situations of the individual states. In authorizing a private cause of action and establishing Protection and Advocacy systems, Congress permitted implementation of the Bill of Rights to be accomplished on a case-by-case basis, taking into account the peculiarities of specific facts and tailoring relief to fit the nuances of the particular jurisdiction and situation.

By mandating that services to developmentally disabled persons be provided in the setting that is the least restrictive while still appropriate to the individual's needs, 42 U.S.C. § 6010(2), Congress sought to ensure that the fundamental right to liberty of such persons is not abridged by the States under the guise of providing services, treatment, or habilitation. By 1975, Congress recognized the need for more drastic measures than previous funding initiatives if developmentally disabled persons were to be given full protection of the law. In response, the Developmental Disabilities Bill of Rights, 42 U.S.C. § 6010, was enacted. The extensive legislative history of this section makes clear that Congress intended to eliminate inappropriate placement in institutions of persons with developmental disabilities.

The State Protection and Advocacy Systems have played an essential role in assuring that developmentally disabled persons obtain full protection of their legal rights. Failure to recognize the enforceability of 42 U.S.C. § 6010 in the circumstances of this case would not only destroy the enforcement

scheme established by Congress, but would seriously undercut the efforts of the P&As by leaving them with a Congressional mandate, but no legal tools for achieving their statutory and state designated purpose.

ARGUMENT

I. IN A UNIQUE AND PROMISING EXERCISE IN FEDERALISM CHARACTERIZED BY SIGNIFICANT DEFERENCE TO THE AUTHORITY AND UNIQUE CHARACTERISTICS OF THE INDIVIDUAL STATES, CONGRESS WROUGHT IN THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 1975 A SET OF ENFORCEABLE RIGHTS OF DEVELOPMENTALLY DISABLED PERSONS AND ESTABLISHED SEVERAL SPECIFIC MECHANISMS, INCLUDING PRIVATE RIGHTS OF ACTION AND STATE PROTECTION AND ADVOCACY AGENCIES, FOR THE ENFORCEMENT OF THESE RIGHTS.

A. The Plain Language and Legislative History of the Developmental Disabilities Assistance and Bill of Rights Act Make Clear that Congress Intended the Developmental Disabilities Bill of Rights to be Enforceable.

The Petitioners make much of their allegation that the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. §§6000 *et. seq.* (1976), is only a funding statute and does not create enforceable rights. Petitioners Br. 14-23. There might be some merit to such a theory if Petitioners were to limit its application to Developmental Disabilities legislation prior to the 1975 Act. But in the 1975 statute, Congress acted with the clear and express intention of creating enforceable rights for developmentally disabled citizens.

1. Prior Developmental Disabilities Legislation.

In 1961 President Kennedy established a President's Panel on Mental Retardation charged with investigating and making recommendations of governmental initiatives needed regarding mental retardation. Following a one-year study, the Panel submitted to the President its report, entitled "A Proposed Program for National Action to Combat Mental Retardation," in 1962.

Based in part upon the recommendations of the Panel, President Kennedy sent to Congress, on February 5, 1963, a special message on Mental Illness and Mental Retardation. In regard to mental retardation, the President presented a proposed legislative package offering a "bold new approach" focusing on three major objectives: (1) to seek out and eradicate the causes of mental retardation; (2) to add to the underlying knowledge and skilled manpower regarding mental retardation; and (3) to strengthen and improve the programs and facilities serving mentally retarded persons. (President's Message, 88th Cong., 1st Sess. *reprinted in* [1963] U.S. Code Cong. & Ad. News 1466, 1467-68 (Feb. 5, 1963)). The President's legislative proposals were clearly conceived as funding statutes:

> [W]ith these objectives in mind . . . I am proposing a new approach . . . to mental retardation. This approach is designed, in large measure, to use Federal resources to stimulate State, local, and private action.

Id. at 1468.

In response to the President's Message, Congress enacted the gist of his recommendations in the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, Pub. L. No. 88-156, § 5, 77 Stat. 275 (1963), and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, Pub. L. No. 88-164, 77 Stat. 282 (1963). These two statutes were the first in a series of mental retardation and developmental disabilities legislation which would eventually come to include the Developmental Disabilities Assistance and Bill of Rights Act of 1975.

In the Maternal and Child Health and Mental Retardation Planning Amendments, *supra*, the maternal and child health provisions of the Social Security Act were expanded to include comprehensive maternity and infant care projects aimed at high-risk mothers and designed to prevent mental retardation. This law also initiated a new program of grants to states to assist them in developing comprehensive state planning in the field of mental retardation.

With Title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, *supra*, Congress launched the first federal program for the construction of facilities for mentally retarded persons. Under

this statute, funds were authorized for federal grants to subsidize the costs of constructing research centers for investigating the causes and prevention of mental retardation, for grants to underwrite costs of constructing university affiliated facilities for mentally retarded people, and for formula grants to the states to pay from one-third to two-thirds of the costs of constructing facilities for the care of mentally retarded persons. In addition to these provisions relating to mental retardation facilities, Title II, entitled the Community Mental Health Centers Construction Act, provided for formula grants to the states to facilitate the construction of community mental health centers.

The programs begun under the 1963 Acts were continued and expanded slightly in the Mental Retardation Facilities and Community Mental Health Centers Construction Act Amendments of 1965, Pub. L. No. 89-105, 79 Stat. 427 (1965), and in the Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286 (1965), pursuant to which funds were authorized for the states to begin implementing the comprehensive mental retardation plans developed with previous funding.

The Mental Retardation Amendments of 1967, Pub. L. No. 90-170, 81 Stat. 527 (1967), extended the programs begun under the 1963 and 1965 legislation until June 30, 1970. In addition, the 1967 Amendments established a new program of matching grants following the same formula as in the Community Mental Health Centers Construction Act to help meet the costs of construction, staffing, or services at community mental retardation centers.

In the Developmental Disabilities Services and Facilities Construction Amendments of 1970, Pub. L. No. 91-517, 84 Stat. 1316 (1970), Congress broadened its concern from simply mental retardation to also include cerebral palsy, epilepsy, or other neurological conditions requiring similar treatment. This enlarged class of persons eligible for services under the statute was denominated "developmentally disabled." To assist this expanded class of disabled persons, Congress replaced the community facilities construction and staffing grant program with a program providing formula grants to the states for comprehensive, coordinated state planning, comprehensive services, and construction of community facilities for developmentally

disabled persons. Pursuant to the requirements of the statute, each state was required to designate a state planning and advisory council, and to prepare a written State Plan which presented a detailed description of services to be rendered and funds to be expended under the Act and of plans for coordination of services rendered under other programs.

The foregoing historical sketch of federal statutory programs relative to mental retardation and developmental disabilities prior to 1975 can be summed up by noting that Congressional activity in those areas consisted almost entirely of federal grant programs to encourage the construction of facilities, training and hiring of staff, research projects, and the coordination and comprehensive planning of services to developmentally disabled persons.

2. Language and Intent of the 1975 Act and Exercise of Congessional Authority Under Section 5 of the Fourteenth Amendment.

In the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. § §6000 *et seq.* (1976), Congress both continued and made a major departure from prior developmental disabilities legislation. Title I of the Act continued the funding initiatives which had characterized the previous statutes. Title II of the Act, however, added a very new dimension - - the establishment of rights. The duality of the statute's structure was described by Senator Williams, Chairman of the Committee on Labor and Public Welfare which considered and recommended passage of S. 462, 94th Cong., 1st Sess. (1975) (the Senate Bill which was the source of the Bill of Rights provisions of the Developmental Disabilities Assistance and Bill of Rights Act), at the time of the Bill's passage in the Senate:

> Title I assists States in their planning toward the provision of services to meet the needs of developmentally disabled individuals . . . . Title II of the bill sets forth a means to assure that the rights of developmentally disabled individuals will be protected.

121 Cong. Rec. 16517 (1975). Senator Williams also made clear that the departure from strictly a funding approach was fully intentional; after discussing the conditions in public residential institutions, he observed:

> While much can be said about the lack of available funds to improve conditions at these institutions, at some point the country must draw the line.

Id. at 16516 (1975). Subsequently, he declared:

> S. 462 provides a framework by which the constitutional rights of residents and other persons with developmental disabilities may be enforced.

Id. at 16517 (1975).

In instituting this establishment of rights approach, Congress proceeded in a very direct, straightforward manner. Not only is 42 U.S.C. §6010 very clear in speaking of "the rights of persons with developmental disabilities," but the Act itself is entitled the "Developmental Disabilities Assistance and *Bill of Rights* Act" (emphasis added), Sec. 111 is entitled "Rights of the Developmentally Disabled," and Title II, in which the Bill of Rights is found, is unambiguously styled "Establishment and Protection of the Rights of Persons with Developmental Disabilities." Congress was unquestionably seeking to establish rights.

As for enforceability of the Bill of Rights provisions, the Joint Conference Report accompanying the 1975 Act was the paragon of clarity in declaring that the rights listed "should be protected and assured by the Congress and the courts." H. R. Conf. Rep. No. 94-473, 94th Cong., 1st Sess. 42 (1975), *reprinted in* 2 [1975] U.S. Code Cong. & Ad. News 943, 961.

The Congressional authority for enacting a Bill of Rights for developmentally disabled persons is also manifest and well-documented–Congress was exercising its power under Section 5 of the Fourteenth Amendment to enforce the rights of equal protection and of liberty. Section 5 states that "Congress shall have power to enforce, by appropriate legislation, the provisions of this article." In recommending passage of S. 462, the source of the Bill of Rights provisions, the Report of the Senate Committee on Labor and Public Welfare declared:

> The Committee is firmly convinced that Congress must take action to ensure the humane care, treatment, habilitation, and protection of mentally retarded and other persons with developmental disabilities. The Federal Government has the responsibility to provide equal protection under the law to all citizens. . . .
>
> Failure of Congress to respond to the needs of persons with developmental disabilities would make a mockery

> of our Nation's progress in such areas as equal protection and individual liberty.

S. Rep. No. 94-160, 94th Cong., 1st Sess. 32-33 (1975).

The theme of enforcement of equal protection was also voiced by many of the Bill's sponsors and advocates at the time of its passage in the Senate. Senator Jennings Randolph, who introduced S. 462 for floor consideration and who chairs the Subcommittee on the Handicapped which held public hearings regarding the Bill, stated:

> The substantive direction of our efforts is toward the goal of equal rights for all handicapped Americans. Legislation such as the Developmentally Disabled Assistance and Bill of Rights Act is one of the cornerstones to the construction of programs that will meet these goals.

121 Cong. Rec. 16515 (1975). Senator Javits declared:

> Progress toward recognition of the basic human and civil rights of the mentally retarded and other developmentally disabled persons has been slow. The Federal Government has largely abrogated its responsibility in this regard and recently the greatest initiatives have come from our courts. . . .
>
> Congress should reaffirm its belief in equal rights for all citizens—including the developmentally disabled. Congress should provide the leadership to change the tragic warehousing of human beings that has been the product of insensitive Federal support of facilities providing inhumane care and treatment of the mentally retarded. The Bill of Rights of S. 462 represents this new direction and begins this reaffirmation.

Id. at 16519. See also remarks of Senator Stafford, 121 Cong. Rec. 16516 (1975).

Moreover, in addition to implementing the right of equal protection, Congress was enforcing the Fourteenth Amendment's guarantee of due process protection for the right of liberty, expounded in previous decisions of this Court.[1] In

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[1] *Addington v. Texas*, 441 U.S. 418, 425 (1979); *Ingraham v. Wright*, 430 U.S. 651, 672-674 (1977); *O'Connor v. Donaldson*, 422 U.S. 563, 573-576 (1975); *Jackson v. Indiana*, 406 U.S. 715, 738 (1972); *Humphrey v. Cady*, 405 U.S. 504, 511-512 (1972); *In re Gault*, 387 U.S. 1, 50 (1967); *Specht v. Patterson*, 386 U.S. 605, 608 (1967).

Shelton v. Tucker, 364 U.S. 479, 488 (1960), this Court declared:

> In a series of decisions this Court has held that, even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end can be more narrowly achieved. The breadth of the legislative abridgment must be viewed in the light of less drastic means for achieving the same basic purpose.

It is precisely to require the states to comply with this framework for protecting the right of liberty that Congress declared as part of the Developmental Disabilities Bill of Rights a right "to have treatment, services, and habilitation provided in the setting that is least restrictive of the person's personal liberty," 42 U.S.C. § 6010(2).

In implementing the rights to equal protection and to liberty under the Fourteenth Amendment in regard to the class of developmentally disabled persons, whom it found to have suffered severe deprivations of these rights in the past, Congress was clearly acting within the scope of its authority under Section 5. Its creation of statutory rights designed to ameliorate deprivations of underlying constitutional rights is exactly the type of legislative action contemplated by Section 5.[2]

---

[2]The Congressional intent to create enforceable rights and, thereby, to give rise to a rights/funding duality in the enforcement approaches utilized in the developmental disabilities legislation was underscored with the enactment of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, P.L. 95-602, 92 Stat. 2955 (1978). The only amendment made to the Bill of Rights by the 1978 Act was a clarification that the rights listed there "are in addition to any constitutional or other rights otherwise afforded to all persons." 42 U.S.C. § 6010, P.L. 95-602, § 507, 92 Stat. 3007. So not only did Congress not shrink away from recognizing that it had created an enforceable Bill of Rights for developmentally disabled individuals in its 1975 Act, but it went even further and declared that the rights listed in the D. D. Bill of Rights are only *some* of the enforceable rights possessed by disabled persons. See also, H.R. Rep. No. 95-1188, 95th Cong., 2d Sess. 7 (1978) *reprinted in* 6 [1978] U.S. Code Cong. & Ad. News 7355, 7362.

In 1980, Senator Javits described Congressional understanding of the purpose and effect of the D. D. Bill of Rights in debates concerning the creation of a similar bill of rights for mentally ill persons:

B. To Achieve Enforcement of the Developmental Disabilities Bill of Rights, While Respecting the Sovereignty and Diversity of the States, Congress Created a Private Right of Action and Authorized the Establishment of State Protection and Advocacy Systems.

1. Respect for States' Rights.

Throughout its history, federal mental retardation and developmental disabilities legislation has been characterized by a sensitivity to the strengths and differences of the individual states. A 1970 Senate Committee Report termed the interaction between the federal government and the states in the Developmental Disabilities program a "partnership":

> One of the most significant characteristics of State plans for the retarded is their individuality. The 50 States have their own priorities based on historical, geographical, or other differences. Each State plan has its strengths and its weaknesses, but all States are ready to move forward. To nurture this potential and realize its fulfillment, the Nation needs evidence of a continuing Federal commitment to the idea of a State-Federal partnership in this area. That commitment must be at least strong as has been manifested in other major areas of Federal involvement, such as health, education and rehabilitation.

S. Rep. No. 91-757, 91st Cong., 2nd Sess. 6 (1970). See also H.R. Rep. No. 91-1277, 91st Cong., 2nd Sess. (1970), *reprinted in* [1970] U.S. Code Cong. & Ad. News 4714, 4719.

The Developmental Disabilities Assistance and Bill of Rights Act of 1975 continued the comprehensive state formula grant programs which offered such opportunities of state-by-

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Footnote 2 continued.

What I tried to do originally was to parallel the experience which we had with the developmentally disabled, in which we found such outrageous conditions on the State level as to assail our consciences so deeply that we had to have some uniform rule respecting the basic and most elementary rights in the United States. And that has worked. We have not had a great deal of litigation under that legislation, which incorporated a set of rights which we gave the individual.

July 24 Cong. Rec. S. 9735 (1980).

state tailoring of funding and services to local needs and conditions. Indeed, a House Committee Report accompanying the 1975 Act was very laudatory toward the formula grant program, calling it "a new, innovative approach to the provision of services to a population such as that with developmental disabilities," applauding the responsibility at state level for developing implementation strategies and the "flexibility" and "variation" among the states this entailed, and praising "the high proportion of funds used for the actual provision of services, the wide variety of different services which have been provided and the large number of individuals who have benefited." H. R. Rep. No. 94-58, 94th Cong., 1st Sess. (1975), *reprinted in* 2 [1975] U.S. Code Cong. & Ad. News 919, 922-923.

But whatever positive aspects there were in the state developmental disabilities programs, the 94th Congress concluded that these were no substitute for recognition and implementation of enforceable legal rights of disabled persons. Consequently, while continuing the "state-federal partnership" in the developmental disabilities formula grant programs, Congress agreed with Senator Williams that "at some point the country must draw the line," 121 Cong. Rec. 16516 (1975), and accordingly it enacted the Developmental Disabilities Bill of Rights.

The Bill of Rights provisions of Title II of the 1975 Act, 42 U.S.C. § 6010, resulted from a compromise worked out in a Joint Congressional Conference. The House version of the Act, H.R. 4005, did not include any Bill of Rights section. The version which passed the Senate, S. 462, included a very lengthy and detailed set of rights of developmentally disabled individuals, comprised of some 117 sections and covering some 336 pages. See S. Rep. No. 94-160, 94th Cong., 1st Sess. 46-76 (1975). Moreover, each of the individual sections was not merely a broad, general statement, but rather a detailed exposition of relatively explicit requirements.

Enactment of the Senate's Bill of Rights would, therefore, have engendered something of a federal preemption of the area of facilities and services for developmentally disabled persons. For, whatever the merit of the substantive requirements in the

Senate bill, it is clear that they would have essentially mandated a high degree of uniformity and standardization in the structure and operation of residential facilities and community services in all the states. Such an eventuality would surely have resulted in improvement in many facilities and services, but at the expense of the states' diversity and individual prerogatives.

In its wisdom, however, Congress decided not to supersede the sovereignty of the states so extensively. The process by which a compromise was reached was sketched in the Joint Conference Report:

> The conference substitute contains a compromise which specifies rights of the developmentally disabled, requires programs assisted under the Act to have individual habilitation plans for those they serve, and requires the States to develop programs for protection and efficacy of the rights of the developmentally disabled. . . . The compromise is drafted as a second title in the conference substitute which amends the Developmental Disabilities Act. . . .
>
> These rights are generally included in the Conference substitute in recognition by the conferees that the developmentally disabled, particularly those who have the misfortune to require institutionalization, have a right to receive appropriate treatment for the conditions for which they are institutionalized, and that this right should be protected and assured by the Congress and the courts.

Joint Explanatory Statement of the Committee of Conference, H. R. Conf. Rep. No. 94-473, 94th Cong., 1st Sess. 41-42 (1975), *reprinted in* 2 [1975] U.S. Code Cong. & Ad. News 943, 961.

Hence, instead of a wholesale overriding of the authority and options of the states by enacting the detailed Senate provisions, the conferees forged a compromise which established certain important rights of developmentally disabled citizens and made these rights enforceable, but still left open to the states opportunities for implementation tailored to the specific needs and peculiar features of particular states. As a result, the Developmental Disabilities Assistance and Bill of Rights Act of 1975 pursues a multi-faceted approach. In Title I of the Act, it continued the program funding aspect of prior developmental

disabilities legislation. At the same time, it specified program standards with which applicants for funds were required to comply to maintain their grant eligibility, 42 U.S.C. §6010(3), (4). In addition, and, most importantly for the purpose of this case, it created mechanisms for the enforcement of the Bill of Rights provisions which take into account the authority and individual differences of the states. In authorizing a private right of action for enforcement of the Developmental Disabilities Bill of Rights, to be discussed in subsection 2 below, Congress permitted implementation of the Bill of Rights to be rendered on a case-by-case basis which takes into account the particular facts and circumstances of the individual situation, and which allows tailoring of relief to fit the peculiarities and nuances of the situation. This is in great contrast with the approach of S. 462 which would have imposed, by federal fiat, uniform structures and practices upon all of the states.

Secondly, to assure that developmentally disabled persons are able to make use of the judicial and administrative machinery available for the enforcement of their rights, Congress created the state Protection and Advocacy Systems (*amici* herein), to be discussed in subsection 3 below, 42 U.S.C. §6012. These Protection and Advocacy Systems have been developed and designated by the individual states according to their needs and desires. The diversity in the structures selected by the states for their Protection and Advocacy agencies was noted in a House Committee Report in 1978:

> There has been substantial variation among the States in the organizational framework they have chosen to carry out this task: 16 States have placed the system within an arm of government (often a department of consumer affairs, a public advocate, or a human rights commission), 1 in a university; 10 have contracted with existing organizations (such as legal aid and the State bar association), and 25 States have new nonprofit organizations established for the sole purpose of carrying out the protection and advocacy functions.

H. R. Rep. No. 95-1188, 95th Cong., 2nd Sess. 5 (1978), *reprinted in* 6 [1978] U.S. Code Cong. & Ad. News 7355, 7359-7360.

The enforcement mechanisms in the 1975 Act are thus very states' rights oriented and, in arguing against the enforcement of the Developmental Disabilities Bill of Rights, Petitioners Br. 11-23, Petitioners should consider that the Congressional alternative to the current formulation is a much more instrusive and onerous delineation of specific requirements on the states as represented by S. 462.

2. Private Right of Action.

Throughout § 6010 and in other parts of the 1975 and 1978 Acts, the rights are referred to as "rights of persons with developmental disabilities" or "rights of the developmentally disabled"; the rights created clearly belong to individual persons and are not merely "standards" or funding prerequisites. See pp. 6-9, *supra*. It seems clear therefore that § 6010 was intended by Congress to create personal rights which are judicially enforceable.

Petitioners' argument that §6010 should only be enforceable by administrative action by the Secretary of Health and Human Services, Petitioners Br. 28-34, thus flies in the face of the express language of the Act and explicit Congressional intent. There is a drastic discrepancy between Petitioners' theory and the statute itself. Indeed, if Petitioners were correct subsections (1) and (2) of §6010 would be meaningless and duplicative of subections (3) and (4) of §6010. On the contrary, however, the statute makes clear the dichotomy intended between subsections (1) and (2) and subsections (3) and (4). The first two subsections create legal rights belonging to developmentally disabled persons, while the latter subjections provide a framework of administratively enforceable requirements for funding recipients. This dichotomy in §6010 was noted by the Third Circuit Court of Appeals in the present case, and by the other federal court which has considered the issue, *Naughton v. Bevilacqua*, 458 F. supp. 610, 616 (D.R.I. 1978) *aff'd.* 605 F.2d 586 (1st Cir. 1979). See also *In re Ackerman*, No. 3-379A 60 (Ind. Ct. of App., Sept. 24, 1980). So, in addition to whatever ramifications §6010 may have regarding eligibility for federal funding, it also gives enforceable rights to developmentally disabled persons.

The enforcement of § 6010 on behalf of a developmentally disabled person falls squarely within this Court's ruling in *Maine v. Thiboutot*, ____ U.S. ____, 100 S.Ct. 2502 (1980), that 42 U.S.C. § 1983, which provides a private right of action for state "deprivation of any rights, privileges, or immunities secured by the Constitution and laws," applies to diverse federal statutes. *Id.* at 100 S.Ct. 2504. Indeed, an action under § 6010 was clearly within the scope of § 1983's purview even prior to the clarification given by the *Maine v. Thiboutot* ruling, because § 6010 explicitly grants "rights" to the affected class and, as discussed in section A(2) above, because § 6010 is designed to enforce the right of equal protection under the Fourteenth Amendment. Thus, unlike the Social Security provision at issue in *Maine v. Thiboutot*, § 6010 is a "federal equal civil rights law," *Greenwood v. Peacock*, 384 U.S. 808, 829-830 (1966), and could be considered within the scope of § 1983 even under the reasoning of the dissenting opinion in *Maine v. Thiboutot*, *Id.* at 100 S.Ct. 2507-2519 (Powell, J., dissenting).[3]

3. State Protection and Advocacy Systems (P & As).

Section 6012 of 42 U.S.C. requires each state to have "a system to protect and advocate the rights of persons with developmental disabilities." The statute specifies further that "such system must (a) have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services,

[3]The clearly expressed intent of Congress to create enforceable rights combined with the application of § 1983 means that developmentally disabled persons were *explicitly* afforded a private right of action under § 6010. There is thus no necessity for considering the criteria under *Cort v. Ash*, 422 U.S. 66, 78 (1975), for the existence of an *implicit* private right of action. See Petitioners' Br. 29, n. 49. It is worth noting, however, that the Third Circuit Court of Appeals, acting prior to this Court's decision in *Maine v. Thiboutot*, held in the present case that the *Cort v. Ash* criteria were met and an implicit private right of action did exist. The court in *Naughton v. Bevilacqua, supra*, reached an identical conclusion that a private right of action exists under § 6010. See also, *Medley v. Ginsberg*, No. 78-2099 CH (S.D.W.Va., June 10, 1980); *In re Ackerman, supra*; and *Henkin v. South Dakota Dept. of Soc. Services*, No. CIV 78-4088 (D.S.D. Sept. 26, 1980).

or habilitation within the State, (b) not be administered by the State Planning Council, and (c) be independent of any agency which provides treatment, services, or habilitation to persons with developmental disabilities." *Id.*[4]

The legislation mandated that the P&As were to be in effect as of October 1, 1977, and by the time of the 1978 Amendments to the Developmental Disabilities Assistance and Bill of Rights Act, fifty-four P&As had been created and were in operation-one in each state, the District of Columbia, and in three U.S. territories.

There is a close nexus between the protection and advocacy function in 42 U.S.C. § 6012 and the private right of action under § 6010 discussed in part 2 above. In light of Congressional awareness that many persons with developmental disabilities "are not able to adequately protect their own rights," S. Rep. No. 94-160, 94th Cong., 1st Sess. 37 (1975), the private cause of action created under § 6010 would not be a completely adequate remedy for all disabled persons. The P&As were created to fill in this potential gap in enforcement of the §6010 private right of action. P&As were, therefore established to implement (among others) the provisions of §6010 by providing protection and advocacy to disabled persons who

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[4] Like § 6010 Bill of Rights provisions, the concept of state protection and advocacy systems (P&As), *amici* herein, had its origin in S. 462. As initially conceived, the Bill would have established "protective and personal advocacy agencies" which were to serve as oversight agencies with authority to monitor programs and services and investigate and render decisions on the merits of complaints. S. Rep. No. 94-160, 94th Cong., 1st Sess. 51-52 (1975).

Like § 6010, the need for advocacy services was one of the important concepts culled from the extensive provisions of Title II of S. 462 and accepted in the Joint Conference compromise which produced the Developmental Disabilities Assistance and Bill of Rights Act of 1975. In conference, however, some changes were made from the Senate's initial concept. Along with a change of name from "Protective and Personal Advocacy Agencies" to simply "Protection and Advocacy Systems," the role of the P&As was altered from that of an investigative and decision-rendering administrative agency to an advocacy agency with the "authority to pursue legal, administrative and other appropriate remedies to insure the protection of the rights of such persons." § 113 of P.L. 94-103, codified at 42 U.S.C. § 6012.

might not be able to successfully perform such an advocacy function by themselves. By mandating and funding the P&A Systems, Congress has underscored and reinforced its intent to make § 6010 enforceable. It is noteworthy that the Public Interest Law Center of Philadelphia, counsel for Respondents Pennsylvania Association for Retarded Citizens and four individual plaintiffs, was, at the time this action commenced, under contract to the Pennsylvania Protection and Advocacy System to advocate for developmentally disabled clients.

The role of the P & As in enforcing §6010 rights has been recognized by several lower courts. *Eg. United States v. Mattson*, 600 F.2d 1295, 1299 (9th Cir. 1979); *United States v. Solomon*, 563 F.2d 1121, 1125 (4th Cir. 1977); *Naughton v. Bevilacqua, supra; Goldstein v. Coughlin*, Civ. 79-256 (W.D.N.Y., Sept. 25, 1979). In both the *Naughton v. Bevilacqua* and *Goldstein v. Coughlin* cases, *supra*, the courts considered the standing of state protection and advocacy systems to bring suit to enforce the Developmental Disabilities Bill of Rights and in each instance the court held that P & As did have such standing. The *Goldstein v. Coughlin* court held that, as the "designated advocacy system" for the state of New York with the Congressional purpose of providing "legal representation," the P & A need show no injury to itself in order to have standing in such an action. *Id.* at 3. In *Naughton v. Bevilacqua, supra*, the court determined that the Rhode Island Protection and Advocacy System had standing to intervene as a party-plaintiff in an action involving enforcement of 42 U.S.C. §6010. Further, the court added that "the advocacy agency and a private right of action are crucial to protect the rights secured by the Act." *Id.* at 458 F. Supp. 616.

The importance of the P & A function in implementing the rights established under §6010's Bill of Rights provisions was also underscored by Senator Kennedy, Chairman of the Senate Judiciary Committee, in arguments made on behalf of P & A continuation funding in 1978:

> . . .the only way change is going to be brought about is the long, difficult, persistent and dedicated advocacy of those who are prepared to follow through administrative hearings, through hearings on regulations, through challenges in the courts, for the rights which are guaranteed in this legislation. That is the way it is done.

124 Cong. Rec. 15663 (1978).

For all of these reasons, it is clear that the private right of action and the state protection and advocacy agencies were intended by Congress as a potent, mutually supportive combination of mechanisms for the enforcement of § 6010.

II. AMONG THE RIGHTS PROTECTED IN THE DEVELOPMENTAL DISABILITIES BILL OF RIGHTS IS THE RIGHT TO HAVE TREATMENT, SERVICES AND HABILITATION PROVIDED IN THE SETTING THAT IS THE LEAST RESTRICTIVE OF THE PERSON'S PERSONAL LIBERTY.

Section 111(2) of the Developmental Disabilities Assistance and Bill of Rights Act plainly states that:

> [t]he treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is the least restrictive of the person's personal liberty.

42 U.S.C. § 6010(2).

From its beginning in 1963 with the passage of the Mental Retardation Facilities and Community Mental Health Centers Act, Pub. L. No. 88-164, 77 Stat. 282 (1963), developmental disabilities legislation consistently has focused upon improving the plight of the thousands of individuals confined to large residential institutions because of disability.

In inspiring the 1963 Act, President Kennedy, in his address to Congress on February 5, 1963, called upon Congress to

> move from the outmoded use of distant custodial institutions to the concept of community-centered agencies that will provide a coordinated range of timely diagnostic, health, education, training, rehabilitation, employment, welfare and legal protection services.

President's Message, 88th Cong., 1st Sess., *reprinted in* [1963] U.S. Code Cong. & Ad. News 1466, 1474 (Feb. 5, 1963). And the 1963 Act did reflect this community-oriented approach. See H.R. Rep. No. 88-694, 88th Cong., 1st Sess., *reprinted in* [1963] U.S. Code Cong. & Ad. News 1054, 1062.

In 1967, Congress definitively expressed its approval for community support services for mentally retarded persons

with the passage of the Mental Retardation Amendments, Pub. L. No. 90-170, 81 Stat. 527 (1967), which provided states Federal financial incentives to develop, construct and staff community mental retardation facilities. The Senate Labor and Public Welfare Committee, citing to advances in research in the cause and treatment of mental retardation, stated, "it is possible, through programs enacted by Congress and by the States, and through private voluntary agencies, to make it possible for a much larger number of the retarded to live with some degree of decency and normalcy in our society." S. Rep. No. 90-725, 90th Cong., 1st Sess., *reprinted in* [1967] U.S. Code Cong. & Ad. News 2061, 2062.

By 1975, Congress had had ample time to reflect upon the success of its efforts to decrease the need for custodial institutions for developmentally disabled persons. The Senate Committee on Labor and Public Welfare vividly expressed its displeasure with the lack of progress in developing community services in its report accompanying S. 462:

> It is now almost 50 years since experts in the field of mental retardation first began to talk about alternatives to large institutions. Unfortunately, progress in developing these community alternatives continues to be slow and—as this Committee repeatedly heard in dramatic testimony from witnesses—the care provided in institutions almost always still leaves much to be desired.

S. Rep. No. 94-160, 94th Cong. 1st Sess. 27 (1975). The Committee explicitly deplored the conditions existing in large residential institutions, repeatedly quoting from and citing to graphic descriptions of institutional life. The institutions were referred to as " 'hopeless places' dedicated to custodial care of lifelong residents." *Id.* at 28.

No doubt was left about the Committee's belief that the process of institutionalization must be halted:

> It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in institutions at all. Efforts to assure proper treatment, education, and habilitation services should not deflect attention from the fact that most of these institutions themselves are anachronisms, and that rapid steps must be taken to phase them

> out. Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education, and habilitation programs.

Id. at 32-33. In the face of such dissatisfaction, the Developmental Disabilities Bill of Rights was enacted.

Concern that the enactment of a set of standards of care to be met in institutional settings would be confused as Congressional approval of institutionalization prompted the Committee to report:

> . . .the intent of this legislation is not only to improve care in residential facilities, but also to minimize inappropriate admissions and to stimulate the States to develop alternative programs of care for mentally retarded and other developmentally disabled persons. It is clear that the provision of adequate and humane care in large State institutions, alone, is not an adequate answer to the problem. Other initiatives must include cutting off the flow of residents into such institutions by development of community alternatives. . . .
>
> The Committee feels that the standards set forth. . . are minimum standards to insure basic human dignity where institutional care for developmentally disabled persons is found. It is not, however, the Committee's intent that enactment of [these standards] should be construed in any way to constitute support of institutionalization of the mentally retarded.

Id. at 33.

The concerns expressed by the Committee were echoed on the floor of the Senate when S. 462 was brought forward for debate and approval.[5] Senator Williams stated that

> . . .the horrible conditions which exist in most of the public residential institutions for the mentally retarded and other developmentally disabled persons have provided shocking testimony to the inhuman ways we care for such persons.

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[5] While the Senate was considering S. 462, the House of Representatives had before it H.R. 4005, 94th Cong., 1st Sess. (1975), a bill designed to extend and expand the programs begun under the 1970 Act. While H.R. 4005 did not contain extensive detailed standards for residential and commercial facilities as in the Senate bill, it plainly supported the development of community-based alternatives to institutionalization. In a significant

121 Cong. Rec. 16516 (1975). Among the abuses occurring at such institutions, he cited that of "[i]nappropriate admissions because of lack of community services." *Id.* Senator Javits declared the purpose of the bill to include "encouraging deinstitutionalization and normalization." *Id.* at 16518. He also observed that the bill was designed to "change the tragic warehousing of human beings that has been the product of insensitive Federal support of facilities providing inhumane care and treatment of the mentally retarded." *Id.* at 16519.

When the compromise legislation, worked out in conference, was presented to Congress for its consideration, strong support was offered for the goals expounded in the bill. Senator Schweiker, citing the need for the legislation, stated:

> [t]he developmentally disabled in this Nation for too long have been treated as burdensome problems, rather than with the affection and care they deserve as human beings. Too often developmentally disabled persons are "put away" in institutions and forgotten. It is now time to provide alternatives to locking people up in institutions.

121 Cong. Rec. 29820-21 (1975). Senator Williams described the bill as assisting "in the process of deinstitutionalization and the protection of rights of persons with developmental disabilities." *Id.* at 29821. See also remarks of Sen. Javits, 121 Cong. Rec. 29820 (1975).

A major effect of 6010(2) is to require the States to provide community services in lieu of institutionalization where such services can meet the needs of the disabled person. Congress has defined the term "alternative community living arrangement services" as "such services as will assist persons with developmental disabilities in maintaining suitable residential

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Footnote 5 Continued.

revision of the 1970 Act, the House legislation required the States to spend a specified percentage of their federally allotted dollars "for programs for deinstitutionalization of persons with developmental disabilities inappropriately placed in institutions." H.R. Rep. No. 94-58, 94th Cong., 1st Sess. 1, *reprinted in* 2 [1975] U.S. Code Cong. & Ad. News 919. In reporting on H.R. 4005, the House Committee on Interstate and Foreign Commerce applauded the efforts on the part of the developmental disabilities programs to establish, assure, and preserve the rights of disabled persons including "the right to live under conditions least restrictive to personal liberty." *Id.* at 925.

arrangements in the community." 42 U.S.C. §6001(8) (E). These support services include "in-house services (such as personal aides and attendants and other domestic assistance and supportive services), family support services, foster care services, group living services, [and] respite care." *Id.*

This requirement of §6010(2) that the states develop and implement alternatives to large-scale institutions for the appropriate treatment of persons with developmental disabilities was underscored clearly by Senator Javits in 1975:

> Mr. President, I believe one very clear basic goal has been enunciated in the legislation reported from committee. That is the need to move away from institutionalization of individuals with development of community-based programs utilizing all community resources related to treatment or habilitation of such individuals to provide comprehensive services in the home community.

121 Cong. Rec. 16520 (1975).

III. A DECISION FOR PETITIONERS ON THIS APPEAL WOULD FRUSTRATE CONGRESSIONAL AND STATE INTENT, UNDERCUT EFFORTS BY STATE PROTECTION AND ADVOCACY SYSTEMS TO ENFORCE THE RIGHTS OF THEIR CLIENTS, AND LEAVE THE PROTECTION AND ADVOCACY AGENCIES WITH A MANDATE BUT NO LEGAL TOOLS FOR ACHIEVING THEIR STATUTORY AND STATE DESIGNATED PURPOSES.

A. Accomplishments of State Protection and Advocacy Systems Enforcing the Rights of Developmentally Disabled Persons.

The State Developmental Disabilities Protection and Advocacy Systems (P & As), *amici* herein, are charged by federal statute and by their state designations with a very important mission - - that of advocating for and protecting the rights of developmentally disabled citizens. 42 U.S.C. §6012; see pp. 15-18, *supra.* In 1978, when continuation funding levels for the P & As were being considered, Senator Kennedy declared:

> The establishment of a protection and advocacy system for the developmentally disabled in 1975 marked a major advance in the movement to assure that the human and legal rights of all developmentally disabled persons would be secured.
>
> No struggle to proclaim and demand fundamental human rights has been harder or more tragic than the struggle of the developmentally disabled, for among such persons - - the mentally retarded, the autistic, the cerebral palsied - - are found some of those most victimized by society's prejudices and least able to be heard effectively.
>
> The P&A system was developed after careful and extensive congressional review of outrageous violations of the rights of the developmentally disabled.

124 Cong. Rec. 15663 (1978). And a General Accounting Office report issued in 1980 concluded that "the State Protection and Advocacy Program could be the most potent and effective mechanism to insure that the developmentally disabled receive the benefits, services, and rights they are entitled to." "How Federal Developmental Disabilities Programs Are Working: Comptroller General's Report to the Subcommittee on the Handicapped, Senate Committee on Labor and Human Resources," 72 (Feb. 20, 1980) (hereinafter G.A.O. Report).[6]

A major problem of the P & As has been inadequate funding resources. *Id.* In its three years of existence, the P & A program has received only "bare-bones" federal funding while outside funding sources for P & A activities have been difficult

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[6]The performance of the P&As in their role of enforcing the Developmental Disability Bill of Rights and other rights of developmentally disabled persons was endorsed by Congress in the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. 95-602, which not only continued the existing P&A program but also authorized the establishment of an additional system "to protect and advocate the rights of severely handicapped individuals," as part of the statutory program of Comprehensive Services for Independent Living under the Rehabilitation Act. 29 U.S.C. § 796g. By replicating the protection and advocacy concept, Congress showed its satisfaction with the role that P&As were playing and sought to afford a similar protection and advocacy service for other citizens.

to obtain. *Id.* at 65-68, 72;H.R. Rep. No. 95-1188, 95th Cong., 2d Sess. 5-6 (1978); see also 124 Cong. Rec. 15663, 15672 (1978). In spite of these difficulties, however, P & As have been able to achieve many concrete accomplishments in protecting the rights of persons with developmental disabilities.

Some of the general types of activities in which P&As have engaged were noted in a House Committee report accompanying the 1978 Developmental Disabilities legislation:

> information and referral, legal remedy pursuits to protect individual rights, "non-legal" advocacy such as advocacy training, assistance to citizen advocacy projects, and encouraging self-advocacy, and various class advocacy activities aimed at systems reform.

H. R. Rep. No. 95-1188, 95th Cong., 2d Sess. 5 (1978), *reprinted in* 6 [1978] U.S. Code Cong. & Ad. News 7355, 7359-7360. The G.A.O. Report, *supra*, noted:

> Two factors which distinguish this program from others–independence and power–also are the key to its success. Being independent of other administering or service agencies, the State Protection and Advocacy Program gives the developmentally disabled a way to work outside established service delivery systems to contest their rights. More importantly, where needed services are not being provided, program advocates can intercede on behalf of the disabled and compel others to furnish such services.

Id. at 72.

Of the overall success of the P & As, Senator Kennedy observed in 1978 that it is a program "which has been extremely successful and which the States, themselves, have warmly embraced and which the handicapped people and the developmentally disabled people of this Nation warmly endorse." 124 Cong. Rec. 15663 (1978). He added that "the evaluation of the existing programs has shown some of the most dedicated, committed individuals involved in these programs," *Id.* And further, "[i]t is a program which is building upon a solid record of achievement and accomplishment. It has wide and broad support of the people that have been affected . . ." *Id.*

A report issued by the Institute for Comprehensive Planning in March of 1980 found that P & As had served some 44,000 developmentally disabled persons during their first two

years of operation. Henney and Alldredge, "Protection and Advocacy in the United States - - The First Two Years," 3, Institute for Comprehensive Planning (March 1980) (hereinafter I.C.P. P & A Report). Of this large number of persons served, only a very small proportion of the cases necessitated legal action, indicating that P & As have not been at all litigation "trigger-happy." Less than 7 percent of the cases handled by P & As during their first two years required legal remedies such as administrative hearings, due process hearings, and court action. *Id.* at 12. And only 1.5 percent of the cases handled involved actual court proceedings. *Id.* The report concluded that "the fact that Protection and Advocacy has used the legal redress judiciously underscores the maturity that this unique and dynamic system has attained in its first two years of operation." *Id.* at 12-13.

The statistics as to the large numbers of individuals served by the P & As can be made more meaningful by a delineation of some concrete, specific examples of the ways in which P & As have helped developmentally disabled clients.

In Maryland, for instance, the Protection and Advocacy system was instrumental in obtaining the release of and appropriate programming for a mentally retarded man who had been misdiagnosed as mentally ill and confined in state mental hospitals for 37 years. He had stopped talking, stopped feeding himself and exhibited other regressive behavior while at the mental facilities. With P & A assistance and the cooperation of state agencies, the Quiet Man (as he came to be called) was allowed to enter a program in the community for mentally retarded persons, where he has not only regained the ability to talk and feed himself but has made much progress in social skills and other areas. Investigation by the Maryland Attorney General has disclosed that the Quiet Man is only one of a number of mentally retarded people being improperly confined in mental illness facilities; the P & A is presently working with the Attorney General's office to assist these persons. The Quiet Man currently lives in the community with an aunt.

In Hawaii, the P &A has placed a staff person and opened a branch office in Calipappa on the island of Molokai to assist the approximately 130 severely handicapped persons who are

the remnants of the once infamous leper colony. Calipappa is located in an extremely isolated site with cliffs barring access except by mule train or helicopter. The P & A is seeking to arrange improved medical care and to secure for the severely disabled residents various state services for which they are eligible.

The Arizona P & A, in conjunction with a state licensing agency, secured the closing of a private nursing facility where thirteen mildly mentally retarded residents had been housed in allegedly extremely substandard and even bizarre circumstances, including the confinement of residents in a corral, stock pens and commodes. *Becker v. Hobby Horse Ranch School*, Civ. 79-303 (D. Ariz. Oct. 29, 1979). After the facility was closed, the Arizona P & A worked successfully with several other state P & As to arrange alternative placements for the residents of the facility.

Several P & As have worked to overcome potential zoning problems and restrictive covenants which have hampered the development of community living arrangements. In *Bellarmine Hills Association v. The Residential Systems Co.*, 84 Mich. App. 554 (1978), for example, the Michigan P & A was able to have a planned foster home for six mentally retarded children upheld as a single family residence complying with a restrictive covenant on the property. The court stressed the important public policy of supporting residential alternatives to institutionalization. And in a somewhat similar context, the Illinois P & A succeeded in reversing a Chicago Zoning Board of Appeals decision which would have denied a special permit for a building to be used for a group home for ten developmentally disabled children.

The Idaho P & A operates a community organization program which serves from 50 to 60 clients. This program involves organization and training of parents of institutionalized persons in regard to the rights of institutionalized persons. As a result of this program, parents initiated negotiations with the administration of a local institution to increase programming and to improve conditions. As a result, programming has been improved and several residents have been discharged to appropriate community programs.

The Delaware P & A intervened on behalf of an older mentally retarded couple who were being denied the right to marry and to live together as husband and wife by the institution in which they both resided, even though they were legally competent and had the requisite personal and social skills to enter into marriage. The efforts of a P & A staff person advocating for the couple's legal rights succeeded in persuading the facility administrators to relent, and the couple was able to get married and to live conjointly. The P & A person not only secured the couple's legal rights, but reportedly also served as a witness and official photographer at their wedding ceremony. While such personal involvement is perhaps above and beyond the call of duty, this example is illustrative of the critical role that P & As often play in convincing service providers to respect the rights of developmentally disabled persons.

The foregoing examples are only the smallest sampling of the diverse and fruitful activities engaged in by the P & As to advocate for the rights of their clientele.[7] On a day-to-day basis, P & As have a great impact upon improvement of the quality of disabled persons' lives and in achieving implementation of their legal rights. In the words of the Institute for Comprehensive Planning P & A Report, *supra*:

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[7] In speaking in favor of continuation funding for the P&As in 1978, Senator Kennedy cited several examples of P&A activities, including the following:

> In New York, a severely mentally retarded adult had been living in the shower room of a State institution for 10 years. The shower room was equipped only with a mattress. The P&A system intervened and the young man has been relocated in another institution where a habilitation program is being developed for him.
>
> In Texas, a 27-year-old woman with cerebral palsy was being physically and sexually abused by her brother and father. The P&A system was responsible for removing her from her home and found placement for her in a community residence program, providing habilitation services.
>
> In New Jersey, a mentally retarded woman who had worked for the State government with distinction for 22 years had never been able to pass a civil service examination. As a result, she was laid off when her agency ran short of funds, even though less productive workers were kept on. The P&A system appealed her case

> The Protection and Advocacy Program, in cooperation with the other elements [of the Developmental Disabilities program], and in some cases singlehandedly, has allowed thousands of individuals who are developmentally disabled to live in a less restrictive environment, to secure an appropriate education, and to enjoy to the limits of their physical and mental capabilities activities within society that they had not heretofore realized prior to the development of the Protection and Advocacy activity within their state.

Id. at 4.

B. Potential Harm of a Decision in Favor of Petitioners.

Amici P & A agencies are very concerned that a reversal of the Circuit Court's decision in the present case would undermine the Congressional intent in enacting the Developmental Disabilities Bill of Rights, impede the intent of the states in designating their P & A agencies, and severely impair the ability of the P & As to effectively carry out their day-to-day activities. Such a situation would leave the P & As with their state and federal mandates to protect and advocate for the rights of disabled persons, but deprive them of important legal tools for accomplishing their statutory mission.

P & As have not employed a litigious approach in representing their clients; indeed, court activity has been held to an absolute minimum. One reason for the success of this non-litigation strategy has been that P & As have been able to negotiate from a position of strength in that their clients' rights were expressly spelled out in §6010. If this Court were to hold §6010 unenforceable, the negotiating position of the

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Footnote 7 continued.

to the State Civil Service Commission and arranged an oral examination for her. She passed it and is now a permanent employee.

In Massachusetts, a 46-year-old man with epilepsy was held in a county jail without bail for 3 months and denied medical attention and medication. As a result he had several seizures and injured himself badly. His family obtained P&A system intervention. As a result, he was released without bail pending trial.

124 Cong. Rec. 15663 (1978).

P & As and their clients would be significantly undercut. The ability of P & As to obtain voluntary compliance and compromise concessions from service providers would be reduced drastically.

Such a result would directly frustrate the specific purpose for which the individual state governments have selected and authorized their P & A systems and the express charge given these state agencies by Congress: "to protect and advocate the rights of persons with developmental disabilities." 42 U.S.C. §6012.

In order not to stultify the Congressional intent expressed in §§6010 and 6012, and the initiatives of the individual states in authorizing and appointing their P & A agencies, the decision of the Circuit Court of Appeals should be upheld.

CONCLUSION

For the foregoing reasons, the decision of the United States Court of Appeals for the Third Circuit should be affirmed.

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Respectfully submitted,

ROBERT L. BURGDORF, JR.
Developmental Disabilities Law Project
500 West Baltimore Street
Baltimore, Maryland 21201
(301) 528-6307

Counsel for Amici Curiae

ON THE BRIEF:

Dawn Oxley Musgrave
Patrick P. Spicer